118TH CONGRESS 1ST SESSION

S. 631

To protect the privacy of personally identifiable health and location data, and for other purposes.

IN THE SENATE OF THE UNITED STATES

March 2, 2023

Ms. Klobuchar (for herself, Ms. Warren, and Ms. Hirono) introduced the following bill; which was read twice and referred to the Committee on Commerce, Science, and Transportation

A BILL

To protect the privacy of personally identifiable health and location data, and for other purposes.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Upholding Protections
- 5 for Health and Online Location Data Privacy Act of
- 6 2023" or the "UPHOLD Privacy Act of 2023".
- 7 SEC. 2. PRIVACY OF HEALTH DATA.
- 8 (a) Prohibition on the Use of Health Data in
- 9 Commercial Advertising.—It shall be unlawful for any
- 10 covered entity to use the health data of an individual that

- 1 is collected from any source (including data volunteered
- 2 by an individual, medical center-derived data, data from
- 3 a wearable fitness tracker, data from web browsing his-
- 4 tory, or any other source determined appropriate by the
- 5 Commission) for commercial advertising.
- 6 (b) Minimization of Collecting, Retaining,
- 7 Using, and Disclosing Health Data.—A covered en-
- 8 tity may not collect, retain, use, or disclose health data
- 9 except—
- 10 (1) with the express consent of the individual to
- 11 whom such data relates; or
- 12 (2) as is strictly necessary to provide a product
- or service that the individual to whom such data re-
- lates has requested from such covered entity.
- 15 (c) Minimization of Employee Access.—A cov-
- 16 ered entity shall restrict access to health data by any em-
- 17 ployee or service provider of the covered entity to only such
- 18 an employee or service provider for which access is nec-
- 19 essary to provide a product or service that the individual
- 20 to whom such data relates has requested from the covered
- 21 entity.
- 22 (d) Privacy Policy.—
- 23 (1) Policy required.—A covered entity shall
- 24 maintain a privacy policy relating to the practices of

- such covered entity regarding the collecting, retaining, using, and disclosing of health data.
 - (2) Publication required.—If a covered entity has a website, such covered entity shall prominently publish the privacy policy described in paragraph (1) on such website.
 - (3) Contents.—The privacy policy described in paragraph (1) shall be clear and conspicuous and contain, at a minimum, the following:
 - (A) A description of the practices of the covered entity regarding the collecting, retaining, using, and disclosing of health data.
 - (B) A clear and concise statement of the categories of such data collected, retained, used, or disclosed by the covered entity.
 - (C) A clear and concise statement of the covered entity's purposes for the collecting, retaining, using, or disclosing of such data.
 - (D) A list of the specific third parties to which the covered entity discloses such data, and a clear and concise statement of the purposes for which the covered entity discloses such data, including how the data may be used by each such third party.

- 1 (E) A list of the specific third parties from 2 which the covered entity has collected such 3 data, and a clear and concise statement of the 4 purposes for which the covered entity collects 5 such data.
 - (F) A clear and concise statement describing the extent to which an individual may exercise control over the collecting, retaining, using, and disclosing of health data by the covered entity, and the steps an individual must take to implement such controls.
 - (G) A clear and concise statement describing the efforts of the covered entity to protect health data from unauthorized disclosure.

15 SEC. 3. UNFAIR AND DECEPTIVE ACTS AND PRACTICES RE-

16 LATING TO LOCATION DATA.

- 17 (a) Prohibition on Sale From Data Brokers.—
- 18 It shall be unlawful for a data broker to sell, resell, license,
- 19 trade, transfer, share, or otherwise provide or make avail-
- 20 able location data (including data volunteered by an indi-
- 21 vidual, medical center-derived data, data from a wearable
- 22 fitness tracker, data from web browsing history, or any
- 23 other source determined appropriate by the Commission).
- 24 (b) Prohibition on Sale to Data Brokers.—It
- 25 shall be unlawful for any person to sell, resell, license,

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1	trade, transfer, share, or otherwise provide or make avail-
2	able location data (including data volunteered by an indi-
3	vidual, medical center-derived data, data from a wearable
4	fitness tracker, data from web browsing history, or any
5	other source determined appropriate by the Commission)
6	to a data broker.
7	SEC. 4. RIGHT OF ACCESS AND DELETION.
8	(a) Right of Access.—
9	(1) In general.—A covered entity shall make
10	available a reasonable mechanism by which an indi-
11	vidual, upon verified request, may access—
12	(A) any health data or location data relat-
13	ing to such individual that is retained by such
14	covered entity, including—
15	(i) in the case of such data that the
16	covered entity collected from any third
17	party, how and from which specific third
18	party the covered entity collected such
19	data; and
20	(ii) such data that the covered entity
21	inferred about the individual; and
22	(B) a list of the specific third parties to
23	which the covered entity has disclosed any
24	health data or location data relating to such in-
25	dividual.

- 1 (2) FORMAT.—A covered entity shall make the 2 information described in paragraph (1) available in 3 both a human-readable and a structured, interoper-4 able, and machine-readable format.
- 5 (b) RIGHT OF DELETION.—A covered entity shall 6 make available a reasonable mechanism by which an indi7 vidual, upon verified request, may request the deletion of 8 any health data or location data relating to such individual 9 that is retained by the covered entity, including any such 10 information that the covered entity collected from a third 11 party or inferred from other information retained by the 12 covered entity.
- 13 (c) Requirements for Access and Deletion.—
- 14 (1) TIMELINE FOR COMPLYING WITH RE15 QUESTS.—A covered entity shall comply with a
 16 verified request received under this section without
 17 undue delay, but not later than 15 days after the
 18 date on which the covered entity receives such
 19 verified request.
 - (2) FEES PROHIBITED.—A covered entity may not charge a fee to an individual for a request made under this section.
- 23 (3) Rules of construction.—Nothing in 24 this section shall be construed to require a covered 25 entity to—

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1	(A) take an action that would convert in-
2	formation that is not health data or location
3	data into health data or location data;
4	(B) collect or retain health data or location
5	data that the covered entity would not other-
6	wise collect or retain; or
7	(C) retain health data or location data
8	longer than the covered entity would otherwise
9	retain such data.
10	(d) Reasonable Mechanism Defined.—In this
11	section, the term "reasonable mechanism" means, with re-
12	spect to a covered entity and a right under this section,
13	a mechanism that—
14	(1) is equivalent in availability and ease of use
15	to that of other mechanisms for communicating or
16	interacting with the covered entity; and
17	(2) includes an online means of exercising any
18	such right.
19	SEC. 5. EXCEPTIONS.
20	(a) Publication of Newsworthy Information
21	OF LEGITIMATE PUBLIC CONCERN.—Nothing in this Act,
22	or a regulation promulgated under this Act, shall apply
23	with respect to health data or location data that is col-
24	lected, retained, used, or disclosed by a covered entity for
25	the publication of newsworthy information of legitimate

- 1 public concern to the public, or to the collecting, retaining,
- 2 using, or disclosing of such data by a covered entity for
- 3 that purpose, if such covered entity has reasonable safe-
- 4 guards and processes that prevent the collecting, retain-
- 5 ing, using, or disclosing of health data or location data
- 6 for commercial purposes other than the publication of
- 7 newsworthy information of legitimate public concern.
- 8 (b) Public Health Campaigns.—The prohibition
- 9 under section 2(a) shall not apply to any public health
- 10 campaign directed toward individuals or subpopulations of
- 11 individuals.
- 12 (c) Disclosure Pursuant to Valid Authoriza-
- 13 TION.—
- 14 (1) IN GENERAL.—Nothing in this Act shall be
- 15 construed to prohibit a disclosure of the health data
- or location data of an individual for which the indi-
- 17 vidual provides valid authorization.
- 18 (2) Valid authorization defined.—For
- purposes of paragraph (1), the term "valid author-
- ization" has the meaning given such term in section
- 21 164.508 of title 45, Code of Federal Regulations (or
- a successor regulation), subject to any such adapta-
- 23 tion the Commission shall deem necessary to apply
- such term to the disclosure of both health data and
- 25 location data.

(d) HIPAA-COMPLIANT ACTIONS.—

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- 2 (1) IN GENERAL.—Nothing in this Act shall be 3 construed to prohibit any action taken with respect 4 to the health information of an individual by a data 5 broker that is a business associate or covered entity 6 that is permissible under the Federal regulations 7 concerning standards for privacy of individually 8 identifiable health information promulgated under 9 section 264(c) of the Health Insurance Portability 10 and Accountability Act of 1996 (42 U.S.C. 1320d-2 note).
- 12 (2) Terms defined.—For purposes of para-13 graph (1), the terms "business associate", "covered 14 entity", and "health information" shall have the 15 meanings given those terms in the Federal regula-16 tions specified in such section 264(c) of the Health 17 Insurance Portability and Accountability Act of 18 1996 (42 U.S.C. 1320d–2 note).

19 SEC. 6. EFFECTIVE DATE.

- 20 (a) In General.—The prohibitions under sections 2
- 21 and 3 shall take effect on the earlier of—
- 22 (1) the date the Commission issues the final 23 rule under subsection (b); or
- 24 (2) 180 days after the date of enactment of this 25 Act.

1 (b) Rulemaking.— 2 (1) Final Rule.—Not later than 180 days 3 after the date of enactment of this Act, the Commis-4 sion shall promulgate regulations, pursuant to sec-5 tion 553 of title 5, United States Code, to carry out 6 the provisions of this Act. 7 (2) Additional Guidance.—The Commission 8 may promulgate further regulations, pursuant to 9 such section 553, to update and carry out the provi-10 sions of this Act, including further guidance regard-11 ing the types of data described in sections 2 and 3. 12 SEC. 7. ENFORCEMENT. 13 (a) Enforcement by the Federal Trade Com-14 MISSION.— 15 (1) Unfair or deceptive acts or prac-16 TICES.—A violation of section 2, 3, or 4 shall be 17 treated as a violation of a rule defining an unfair or 18 a deceptive act or practice under section 18(a)(1)(B) 19 of the Federal Trade Commission Act (15 U.S.C. 20 57a(a)(1)(B). 21 (2) Powers of the commission.— 22 (A) IN GENERAL.—Except as provided in 23 subparagraphs (D) and (E), the Commission 24 shall enforce this Act and any regulation pro-

mulgated thereunder in the same manner, by

- the same means, and with the same jurisdiction, powers, and duties as though all applicable terms and provisions of the Federal Trade Commission Act (15 U.S.C. 41 et seq.) were incorporated into and made a part of this Act.
 - (B) Privileges and immunities.—Subject to subparagraph (F), any covered entity or data broker who violates this Act or any regulation promulgated thereunder shall be subject to the penalties and entitled to the privileges and immunities provided in the Federal Trade Commission Act (15 U.S.C. 41 et seq.).
 - (C) AUTHORITY PRESERVED.—Nothing in this Act shall be construed to limit the authority of the Federal Trade Commission under any other provision of law.
 - (D) Scope of Jurisdiction.—Notwithstanding section 4, 5(a)(2), or 6 of the Federal Trade Commission Act (15 U.S.C. 44, 45(a)(2), 46), or any jurisdictional limitation of the Commission, the Commission shall also enforce this Act and the regulations promulgated under this Act, in the same manner provided in subparagraph (A), with respect to—

1	(i) common carriers subject to the
2	Communications Act of 1934 (47 U.S.C.
3	151 et seq.) and Acts amendatory thereof
4	and supplementary thereto; and
5	(ii) organizations that are not orga-
6	nized to carry on business for their own
7	profit or that of their members.
8	(E) Independent litigation author-
9	ITY.—In any case in which the Commission has
10	reason to believe that a covered entity or data
11	broker is violating or has violated section 2, 3,
12	or 4, the Commission may bring a civil action,
13	subject to subsection (c), to—
14	(i) enjoin any further such violation
15	by such covered entity or data broker;
16	(ii) enforce compliance with this Act,
17	including through deletion of the relevant
18	information;
19	(iii) obtain a permanent, temporary,
20	or preliminary injunction;
21	(iv) obtain civil penalties;
22	(v) obtain damages (whether actual,
23	punitive, or otherwise), restitution,
24	disgorgement of unjust enrichment, or

1	other compensation on behalf of aggrieved
2	persons; or
3	(vi) obtain any other appropriate equi-
4	table relief.
5	(F) CIVIL PENALTIES.—In addition to any
6	other penalties as may be prescribed by law, a
7	violation of this Act shall carry a civil penalty
8	not to exceed 15 percent of the revenues earned
9	during the preceding 12-month period by the
10	ultimate parent entity of the covered entity or
11	data broker that committed such violation.
12	(b) PRIVATE RIGHT OF ACTION.—
13	(1) In general.—Any individual alleging a
14	violation of this Act or a regulation promulgated
15	thereunder may bring a civil action, subject to sub-
16	section (c).
17	(2) Relief.—In a civil action brought under
18	paragraph (1) in which the plaintiff prevails, the
19	court may award—
20	(A) damages in an amount equal to the
21	greater of—
22	(i) actual damages; or
23	(ii) an amount equal to not less than
24	\$100 and not more than \$1,000 per viola-
25	tion, per day;

1	(B) punitive damages;
2	(C) restitution or other compensation;
3	(D) reasonable attorney's fees, including
4	litigation expenses, and costs; and
5	(E) any other relief determined appro-
6	priate by the court, including equitable or de-
7	claratory relief.
8	(3) Injury in fact.—A violation of this Act or
9	a regulation promulgated thereunder with respect to
10	health data or location data constitutes a concrete
11	and particularized injury in fact to the individual to
12	whom such data relates.
13	(4) Invalidity of pre-dispute arbitration
14	AGREEMENTS AND PRE-DISPUTE JOINT-ACTION
15	WAIVERS.—
16	(A) In General.—Notwithstanding any
17	other provision of law, no pre-dispute arbitra-
18	tion agreement or pre-dispute joint-action waiv-
19	er shall be valid or enforceable with respect to
20	a dispute arising under this Act.
21	(B) APPLICABILITY.—Any determination
22	as to whether or how this paragraph applies to
23	any dispute shall be made by a court, rather
24	than an arbitrator, without regard to whether

1	such agreement purports to delegate such deter-
2	mination to an arbitrator.
3	(C) Definitions.—For purposes of this
4	paragraph:
5	(i) Pre-dispute arbitration
6	AGREEMENT.—The term "pre-dispute arbi-
7	tration agreement" means any agreement
8	to arbitrate a dispute that has not arisen
9	at the time of the making of the agree-
10	ment.
11	(ii) Pre-dispute Joint-action
12	WAIVER.—The term "pre-dispute joint-ac-
13	tion waiver" means an agreement that
14	would prohibit a party from participating
15	in a joint, class, or collective action in a ju-
16	dicial, arbitral, administrative, or other
17	forum, concerning a dispute that has not
18	yet arisen at the time of the making of the
19	agreement.
20	(c) Exclusive Jurisdiction.—
21	(1) DISTRICT COURTS.—For any action brought
22	under this Act, the following district courts shall
23	have exclusive jurisdiction:

1	(A) Commission.—For actions brought by
2	the Commission, the United States District
3	Court for the District of Columbia.
4	(B) Private actions.—For private ac-
5	tions brought by individuals, in the court of the
6	plaintiff's choice between—
7	(i) the United States District Court
8	for the District of Columbia; or
9	(ii) the district court of the United
10	States for the judicial district in which the
11	violation took place or in which any de-
12	fendant resides or does business.
13	(2) Court of appeals.—The United States
14	Court of Appeals for the District of Columbia Cir-
15	cuit shall have exclusive jurisdiction of appeals from
16	any decision under paragraph (1).
17	(d) STATUTE OF LIMITATIONS.—An action for a vio-
18	lation of this Act may be commenced not later than 6
19	years after the date upon which the plaintiff obtains actual
20	knowledge of the facts giving rise to such violation.
21	SEC. 8. DEFINITIONS.
22	(a) In General.—In this Act:
23	(1) Collect.—The term "collect" means, with
24	respect to health data or location data, to obtain
25	such data in any manner.

1	(2) Commercial advertising.—The term
2	"commercial advertising" means communications
3	that promote the sale of or interest in goods or serv-
4	ices, including goods or services that are published
5	digitally, via video or audio, or in print.
6	(3) Commission.—The term "Commission"
7	means the Federal Trade Commission.
8	(4) Covered entity.—
9	(A) IN GENERAL.—The term "covered en-
10	tity" means any entity that—
11	(i) is engaged in activities in or affect-
12	ing commerce (as defined in section 4 of
13	the Federal Trade Commission Act (15
14	U.S.C. 44)); and
15	(ii) is—
16	(I) a person, partnership, or cor-
17	poration subject to the jurisdiction of
18	the Commission under section $5(a)(2)$
19	of the Federal Trade Commission Act
20	(15 U.S.C. 45(a)(2)); or
21	(II) notwithstanding section 4,
22	5(a)(2), or 6 of the Federal Trade
23	Commission Act (15 U.S.C. 44,
24	45(a)(2), $46)$ or any jurisdictional
25	limitation of the Commission—

1	(aa) a common carrier sub-
2	ject to the Communications Act
3	of 1934 (47 U.S.C. 151 et seq.)
4	and all Acts amendatory thereof
5	and supplementary thereto; or
6	(bb) an organization not or-
7	ganized to carry on business for
8	its own profit or that of its mem-
9	bers.
10	(B) Exclusions.—The term "covered en-
11	tity" does not include an entity that is—
12	(i) a covered entity, as defined in sec-
13	tion 160.103 of title 45, Code of Federal
14	Regulations (or a successor regulation), to
15	the extent such entity is acting as a cov-
16	ered entity under the HIPAA privacy regu-
17	lations (as defined in section 1180(b)(3) of
18	the Social Security Act (42 U.S.C. 1320d-
19	9(b)(3));
20	(ii) an entity that is a business asso-
21	ciate, as defined in section 160.103 of title
22	45, Code of Federal Regulations (or a suc-
23	cessor regulation), to the extent such enti-
24	ty is acting as a business associate under

1	the HIPAA privacy regulations (as defined
2	in such section 1180(b)(3)); or
3	(iii) an entity that is subject to re-
4	strictions on disclosure of records under
5	section 543 of the Public Health Service
6	Act (42 U.S.C. 290dd-2), to the extent
7	such entity is acting in a capacity subject
8	to such restrictions.
9	(5) Data broker.—The term "data broker"
10	means an individual or entity that—
11	(A) collects, buys, licenses, or infers data
12	about an individual; and
13	(B) sells, licenses, or trades such data.
14	(6) Disclose.—The term "disclose" means,
15	with respect to health data or location data, for a
16	covered entity to release, transfer, sell, provide ac-
17	cess to, license, or divulge such data in any manner
18	to a third party or government entity.
19	(7) Express consent.—
20	(A) IN GENERAL.—The term "express con-
21	sent" means, with respect to the collecting, re-
22	taining, using, or disclosing of health data or
23	location data, the informed, opted-in, voluntary,
24	specific, and unambiguous written consent of an
25	individual (which may include written consent

1	provided by electronic means) to such collecting,
2	retaining, using, or disclosing of such data.
3	(B) Exclusions.—The term "express
4	consent" does not include any of the following:
5	(i) Consent secured without first pro-
6	viding to the individual a clear and con-
7	spicuous disclosure, apart from any privacy
8	policy, terms of service, terms of use, gen-
9	eral release, user agreement, or other simi-
10	lar document, of all information material
11	to the provision of consent.
12	(ii) Hovering over, muting, pausing,
13	or exiting a given piece of content.
14	(iii) Agreement obtained through the
15	use of a user interface designed or manipu-
16	lated with the substantial effect of sub-
17	verting or impairing user autonomy, deci-
18	sion making, or choice.
19	(8) HEALTH DATA.—The term "health data"
20	means data that identifies, relates to, describes, or
21	reveals—
22	(A) the search for, attempt to obtain, or
23	receipt of any health services;
24	(B) any past, present, or future disability,
25	physical health condition, mental health condi-

- tion, or health condition of an individual, including efforts to research or obtain health services or supplies (including location data that might indicate an attempt to acquire or receive such information services or supplies);
 - (C) any treatment or diagnosis of a disability or condition described in subparagraph (B); or
 - (D) any information described in subparagraph (A) through subparagraph (C) that is derived or extrapolated from non-health information (such as proxy, derivative, inferred, emergent, or algorithmic data).

(9) Location data.—

- (A) IN GENERAL.—The term "location data" means data derived from a device or technology that reveals the past or present physical location of an individual or device with sufficient precision to identify street-level location information of the individual or device within 1,850 feet or less.
- (B) EXCLUSION.—The term "location data" does not include geolocation information identifiable or derived solely from the visual content of a legally obtained image, including

1	the location of the device that captured such
2	image.
3	(10) Service Provider.—
4	(A) In general.—The term "service pro-
5	vider" means an individual or entity that—
6	(i) collects, retains, uses, or discloses
7	health data for the sole purpose of, and
8	only to the extent that such individual or
9	entity is, conducting business activities or
10	behalf of, for the benefit of, under instruc-
11	tion of, or under contractual agreement
12	with a covered entity and not any other in-
13	dividual or entity; and
14	(ii) does not divulge health data to
15	any individual or entity other than such
16	covered entity or a contractor to such serv-
17	ice provider bound to information proc-
18	essing terms no less restrictive than terms
19	to which such service provider is bound.
20	(B) LIMITATION OF APPLICATION.—Such
21	individual or entity shall only be considered a
22	service provider in the course of activities de-
23	scribed in subparagraph (A)(i).
24	(C) MINIMIZATION BY SERVICE PRO-
25	VIDERS.—For purposes of section 2, a request

1	from an individual to a covered entity for a
2	product or service, and an express consent from
3	the individual to the covered entity, shall be
4	treated as having also been provided to the
5	service provider of the covered entity.
6	(11) STATE.—The term "State" means each of
7	the several States, the District of Columbia, each
8	commonwealth, territory, or possession of the United
9	States, and each Federally recognized Indian Tribe.
10	(12) Third party.—The term "third party"
11	means, with respect to the disclosing or collecting of
12	health data, any individual or entity that is not—
13	(A) the covered entity that is disclosing or
14	collecting such information;
15	(B) the individual to whom such informa-
16	tion relates; or
17	(C) a service provider.
18	(13) Ultimate parent entity.—The term
19	"ultimate parent entity" has the meaning given the
20	term in section 801.1 of title 16, Code of Federal
21	Regulations (or a successor regulation).
22	(b) Rulemaking.—
23	(1) In general.—Not later than 180 days
24	after the date of enactment of this Act, the Commis-
25	sion shall conduct a rulemaking pursuant to section

- 1 553 of title 5, United States Code, to define the 2 terms "public health campaign" and "data" for pur-3 poses of implementing and enforcing this Act.
- 4 (2) REQUIREMENT.—For purposes of the rule-5 making required under paragraph (1), the term 6 "data" shall include information that is linked, or 7 reasonably linkable, to—
- 8 (A) specific individuals; or
- 9 (B) specific groups of individuals who 10 share the same place of residence or internet 11 protocol address.

12 SEC. 9. RELATIONSHIP TO FEDERAL AND STATE LAWS.

- 13 (a) Federal Law Preservation.—Nothing in this 14 Act, or a regulation promulgated under this Act, shall be 15 construed to limit any other provision of Federal law, ex-16 cept as specifically provided in this Act.
- 17 (b) STATE LAW PRESERVATION.—
- 18 (1) IN GENERAL.—Nothing in this Act, or a 19 regulation promulgated under this Act, shall be con-20 strued to preempt, displace, or supplant any State 21 law, except to the extent that a provision of State 22 law conflicts with a provision of this Act, or a regu-23 lation promulgated under this Act, and then only to 24 the extent of the conflict.

1 (2)GREATER PROTECTION UNDER STATE 2 LAW.—For purposes of this subsection, a provision 3 of State law does not conflict with a provision of this 4 Act, or a regulation promulgated under this Act, if 5 such provision of State law provides greater privacy protection than the privacy protection provided by 6 7 such provision of this Act or such regulation.

8 SEC. 10. SEVERABILITY CLAUSE.

If any provision of this Act, or the application thereof to any individual, entity, or circumstance, is held invalid, the remainder of this Act, and the application of such provision to other persons not similarly situated or to other circumstances, shall not be affected by the invalidation.

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